**NHS BLOOD AND TRANSPLANT**
**ORGAN DONATION & TRANSPLANTATION DIRECTORATE**

# THE FOURTEENTH MEETING OF THE BOWEL ADVISORY GROUP MEETING AT 11:30 AM ON WEDNESDAY 12 OCTOBER 2016, CORAM CAMPUS, 41 BRUNSWICK SQUARE, LONDON, WC1N 1AZ

**PRESENT:**

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| Prof Peter Friend | **Chairman** |
| Dr Elisa Allen | Statistics & Clinical Studies, NHSBT |
| Ms Carly Bambridge | Recipient Co-ordinator Representative |
| Mr Jeremy Brown | Deputy for Ms Susan Richards, Specialist Nurse Organ Donation Rep |
| Mr Andrew Butler | Cambridge Intestinal Transplant Centre |
| Ms Melissa D'Mello | Lay Member |
| Prof John Forsythe | Associate Medical Director |
| Prof Sue Fuggle | Scientific Advisor, ODT |
| Dr Edmund Jessop | Public Health Advisor |
| Dr Simon Gabe | Adult and small bowel and BAPEN Rep |
| Ms Jackie Green | Deputy for Lydia Holdaway, Recipient Co-ordinator Rep |
| Dr Girish Gupte | Birmingham Intestinal Transplant centre, Physician |
| Dr Susan Hill | Paediatric gastroenterologist and BSPGHAN Rep |
| Dr Jonathan Hind | King's Intestinal Transplant Centre |
| Mr Luke Jones | Deputy for Ms Anne Sheldon, Transplantation Support Services Rep |
| Prof Elizabeth Murphy | Lay Member |
| Mr Srikanth Reddy | Consultant Transplant Surgeon, Oxford |
| Dr Lisa Sharkey | Deputy for Dr Steve Middleton, Cambridge Intestinal Transplant Centre |
| Mr Khalid Sharif | Birmingham Intestinal Transplant Centre |
| Prof Simon Travis | Oxford Intestinal Transplant Centre |
| Mr Hector Vilca-Melendez | King's Intestinal Transplant Centre |
| Ms Sarah Watson | Deputy for Dr Edmund Jessop, Public Health Advisor |

**IN ATTENDANCE:**

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|---|---|
| Mrs Kamann Huang | Secretary, NHSBT |

**ACTION**

**Apologies were received from**:
Dr Martin Barnardo, Prof John Dark, Ms Lydia Holdaway, Dr Steve Middleton, Ms Susan Richards, Ms Anne Sheldon and Mr Anthony Snape

## 1 DECLARATIONS OF INTEREST IN RELATION TO AGENDA – BAG(16)1

1.1 There were no declarations of interest in relation to the agenda.

## 2 MINUTES OF THE BAG MEETING ON 2 MARCH 2016 – BAG(M)(16)1

### 2.1 Accuracy

2.1.1 The minutes of the meeting held on 2 March 2016 were agreed as an accurate record of the meeting following the amendment below:

Page 1, Add 'Prof Sue Fuggle to the Attendance list'.

### 2.2 Action Points – BAG(AP)(16)2

2.2.1 All action points have been completed, are in hand or are referred to in the Agenda, apart from the following:

**AP2 – Item 2 – Request for prospective donor data to a project in Germany**
L Sharkey reported that there was reluctance to put UK data into the international domain therefore BAG will not participate in the project.

**AP7 Adolescent transition in small bowel transplantation.**
The BAPEN report for this area has not been published for a couple of years. E Jessop reported that the information should be available for the next meeting.
Refer to Agenda Item 6.

**AP9 – Update on postcode analysis of registered patients.** There was no new information to report. The HIFNET re-organisation of intestinal failure services should improve the equity of access to intestinal failure management and referral for transplantation; however, this is still not established.

### 2.3 Matters arising, not separately identified

2.3.1 There were no matters arising.

## 3 ASSOCIATE MEDICAL DIRECTOR'S REPORT

### 3.1 Developments in NHSBT

3.1.1
- Mike Gumn - Head of Information Services, 12-month fixed-term basis.
- Dr Nicky Anderson - Associate Medical Director for Blood Donation. The Blood Donation structure has been split into two regions; North and South. Matt Jones will lead the South Region and Jane Pearson will remain as the North Region Lead
- Dr Sarah Morley - Associate Medical Director for Manufacturing and Logistics.

### 3.2 Governance

#### 3.2.1 Non-compliance with allocation

3.2.1.1 In the absence of J Dark, P Friend reported that he was not aware of any non-compliances with allocation.

#### 3.2.2 Detailed analysis of incidents for review – BAG(16)17

3.2.2.1 There were no incidents brought up for review.

With regards to the incident of an incorrect offering sequence between Gp1 and Gp2 patients, the Duty Office stated that a manual fix has now been built in for Gp2 patients. The new matching run will take this into account in the next three months.

**ACTION**

3.3 **IT Progress Report – BAG(16)18**

3.3.1 A report giving the progress of IT projects was submitted to members.

S Reddy highlighted an issue of error transcription from one record to another. One option would be for donor teams to cross check. Alternatively another option would be to insert a drop down box on the electronic form for specialist nurses to fill in specific details and for an automatic prompt to ask the question if this information is correct and final before exiting the section.

The cardiothoracic allocation algorithm will be going live towards the end of October.

## 4 STATISTICS & CLINICAL STUDIES REPORT

4.1 **Summary from Statistics and Clinical Studies and Annual Report – BAG(16)19**

4.1.1 E Allen is providing statistical support to the Fixed Term Working Unit looking at the National Bowel Allocation Scheme with regards to small adults and children led by E Murphy. The first meeting had been scheduled for 18 October 2016.

There was discussion about the accuracy of recording of the precise details of which organs were transplanted. The Duty Office requires this information within 72 hours; the donor record is then closed. Recipient Co-ordinators will be reminded of the importance of recording correct information and to report any problems to Statistics and Clinical Studies. It was suggested that this information should be collected at the end of the operation, as it is clear by this stage (to Co-ordinators) what organs have been transplanted (as opposed to retrieved). It was pointed out that, for a surgeon who has completed a very prolonged operation, the requirement to fill in four forms is likely to lead to mistakes.
C Bambridge agreed to propose a solution incorporating the various views of co-ordinators, surgeons etc. **C Bambridge**

4.2 **Potential bowel donors and location – BAG(16)20**

4.2.1 An annual summary was presented detailing donors after brain death (DBD) who met criteria for bowel donation (age < 56 years and weight < 80 kg).

Data had been analysed for the previous two years. Table 1 showed there had been a decrease in the offering rate most noticeable in patients weighing less than 50 kg.

Table 3 detailed the reasons for 12 bowels from small donors that had been declined. The most common reason given by adult centres was donor history. For paediatric centres the most common reason was donor size.

Local exclusion criteria. A Butler raised the issue of >80 kg donors being offered when the limit is <80 kg. It was stated that this is most probably an electronic issue with the algorithm in the computer and the system cannot apply exclusion criteria by centre. Though

**ACTION**

co-ordinators can manually over-ride the decision. L Jones will look further into the exclusion criteria. E Allen to take forward the changes. **L Jones E Allen**

There was concern that surgeons were being phoned up in the middle of the night with offers that were outside the acceptance criteria. It was agreed that it was necessary to have a system that enabled individual patient exclusion criteria. A local solution could be for co-ordinators not to pass on offers outside of the individual patient criteria.

Regarding generic criteria, G Gupte and K Sharif agreed to come up with contra-indications for the paediatric centres and A Butler and S Reddy for the adult centres. **G Gupte/ K Sharif/ A Butler/ S Reddy**

The initiative to obtain more organs for research is being managed in another forum - RINTAG through a Work Group (WG) to include E Murphy as a Lay Member.

## 5 UPDATE FROM WORKING GROUPS

### 5.1 Update from the National Bowel Allocation Working Group

5.1.1 E Murphy will provide feedback following the first meeting to be held on Tuesday 18 October 2016

### 5.2 Update from the Quality of Life Working Group

5.2.1 The importance of Quality of Life measure in intestinal transplantation was unanimously agreed. L Sharkey reported that the criteria are being established. D Massey (Cambridge) and Phil Allen (Oxford) are involved and J Hind (paediatric rep) and M D'Mello (Lay Member) will be invited to the meetings. It was noted that it would also be beneficial to include the burden of care as a metric. It was recommended that the next meeting should be a face to face meeting. **D Massey**

### 5.3 Update from the Working Group on NHSBT data and post-operative data collection

5.3.1 The WG led by S Reddy, includes H Vilca-Melendez from Kings (Adult) A Butler from Cambridge (Adult) and G Gupte from Birmingham (Paediatrics) with statistical support from E Allen. It was stated that E Murphy and/or M D'Mello (Lay members) would provide opinion/ feedback.

### 5.4 Update from the Working Group on a consent document for all types of intestinal transplantation for patient information

5.4.1 A Butler reported that a draft information document had been written which will form part of the consent process. The aim is to come up with a national consent document to remove discrepancies regarding consent between centres. K Huang agreed to circulate the document sent by L Sharkey to members for feedback by 2 November 2016. The current document is around 7 pages long and will need to be shortened. It was recommended that the WG should collaborate with the Pancreas WG led by James Gilbert. It is assumed that the final document will be discussed at the Advisory Group Chairs' Meeting. **K Huang**

**ACTION**

## 6 ADOLESCENT TRANSITION IN SMALL BOWEL TRANSPLANTATION

6.1 **Discussed**

S Watson reported that the adolescent transition process as well as arrangements for long-term care of transplant recipients will continue as before. It was commented that ongoing care and the cost of transitioning from paediatric to adult care should sit within the Service and patients should not have to return to the centre where they were transplanted.

Two issues were raised. Cambridge reported that they had been told explicitly they must not accept transition patients for ongoing care. It was made clear that the issue of transitioning remains with the Trusts. It was agreed to identify the number of patients who are affected at his centre. **K Sharif**
Frustration was raised that this situation had not been resolved over several years, despite recognition of the adverse consequences.
A Butler will forward the relevant communications to E Jessop and S Watson. E Jessop will be visiting Cambridge in November, and this will be an opportunity to discuss further. **A Butler**

## 7 UPDATE ON NEONATAL ORGAN DONORS – MINIMUM GESTATIONAL AGE AND WEIGHT CRITERIA

7.1 G Gupte reported that the Cardiothoracic Group had now set the criteria for minimum gestational age and weight and that these are in agreement with views in Birmingham. This definition is 38 weeks gestational age and 3 kg in weight.

## 8 UPDATE ON POSTCODE ANALYSIS OF REGISTERED PATIENTS – BAG(16)21

8.1 NHSBT ODT cannot give advice on this topic but can provide statistical analysis. It was notable that London has the highest registration rate but the lowest transplant rate. Conversely, the North East of England has the highest transplant rate with a moderate registration rate.

E Jessop will email the metric used by NHS England to E Allen and K Huang. **E Jessop**

## 9 APPEALS/PRIORITY

9.1 There were no appeals regarding bowel intestinal transplantation.

## 10 UPDATE ON ADULT AND PAEDIATRIC SERVICE SPECIFICATION

10.1 G Gupte to send the Service Specification for Paediatrics to K Huang for circulation to members for comment. **G Gupte/ K Huang**

S Watson reported that the Service template had changed with the requirement now to stipulate transition and service care in the Specification for Adults. Centres will now be financed for long-term immuno-suppression.

L Sharkey reported that an IFR (Individual Funding Request) had been sent to NHS England with no response. E Jessop requested the details to be resent to him. Clinically Critically Urgent funding requests is a routine commissioned pathway by NHS England that can be taken up **L Sharkey**

**ACTION**

but the patient has to be at high risk of death within 3 months. E Jessop will email the link to K Huang for circulation to members. **E Jessop/ K Huang**

## 11 ORGAN SPECIFIC REPORT FOR NHS ENGLAND – BAG(16)22

11.1 The annual report on intestine transplantation for the last financial year was presented to members.

S Reddy raised a concern regarding the validity of the risk adjusted outcome data which had very wide confidence intervals, owing to the small numbers. Risk adjustment figure reflects the type of transplant i.e. modified multi-visceral, multi visceral and small bowel. Following discussion it was agreed that E Allen would remove the risk adjusted figures in the tables and re-circulate to members for comment. **E Allen**

E Allen will circulate the on–line survey to members requesting feedback on what data should be published. **E Allen**

## 12 ABDOMINAL WALL ALONE OFFERING SEQUENCE

12.1 A case was raised regarding listing a patient for abdominal wall only transplant. SNODS currently do not routinely consent for this type of transplant. P Friend stated that this is not a nationally funded service and that a simple and pragmatic solution was needed. It was felt that the Transplant Policy need not be rewritten to accommodate this single case, which should be classified as a composite tissue allograft.

## 13 ANY OTHER BUSINESS

13.1 **Pancreas, Liver and National Retrieval Rep on the Bowel Advisory Group**

In order to comply with the Terms of Reference for BAG to have full representation, A Butler agreed to be the Pancreas representative and P Friend will be the representative for National Retrieval and for Liver.

13.2 **Intestinal representation in Hub stakeholder groups**

J Hind agreed to be the BAG representative on the Hub stakeholder group to ensure any issues for intestine transplantation are covered.

13.3 **Retrieval for paediatric bowel graft nationally**

K Sharif raised the issue of centres cross-covering each other for bowel retrieval. However, this was not supported by other centres. They preferred, in general, to retrieve the organs that they implant, given the small numbers.

13.4 **HLA DSA (Donor Specific Antibody)**

Currently HLA DSA (Donor Specific Antibody) data are collected nationally for islet transplantation. S Fuggle raised the question of similar data being collected in Bowel transplantation. The recommendation is to use the same framework agreed by the Pancreas Islet Steering Group. Members were in agreement with the proposal. S Fuggle will write to the intestinal transplant centres and relevant H&I laboratories so that data collection can commence. **S Fuggle**

**ACTION**

13.5 **NASIT Forum**

P Friend noted that the NASIT Forum had progressively acquired the status of an MDT, and that this was now the means of seeking approval for transplantation. This de facto regulatory role requires that NASIT has a better defined constitution, whereas to-date the forum has been run on a rotating basis, with all secretariat functions being provided by the hosting institution. It was agreed that a more formal arrangement was needed. E Jessop agreed to look into precedents and report back. **E Jessop**
S Gabe will email the Terms of Reference for 2010 to P Friend. The question of whether paediatric patients should be included in the same setting was raised. It was suggested that as there was no commonality between patients, this may not add value. It was agreed that this issue required further discussion. S Gabe and G Gupte agreed to discuss and and bring back to the next meeting in March 2017. **S Gable/ G Gupte**

P Friend stated that it would be beneficial to have a five year plan of where we are trying to get to strategically i.e. where national intestinal transplantation should be going. Members agreed to bring a plan to the next meeting. **Centre Reps**

13.6 **Name for Bowel Advisory Group**

With the addition of Composite Tissue to the responsibilities of the group, P Friend invited possible names for renaming the Bowel Advisory Group. Initial suggestions were: CABAG, MVCTAG, MCTAG (Multi-visceral and Composite Tissue Advisory Group) or ICTAG (Intestinal and Composite Tissue Advisory Group).

Members were requested to email P Friend with any further suggestions. **Centre Reps**

13.7 **Annual National Intestinal Transplant Forum**

J Hind informed members that the next National Bowel Transplant Forum will be held at King's College Hospital on Tuesday 10th January 2017 at King's College Hospital. The plan is to present joint work for abstracts (closing date 27th January) for the CIRTA 2017 meeting later in the year (see Item 13.8 below).

13.8 **15th International Congress of the Intestinal Rehabilitation & Transplant Association (CIRTA)**

The next CIRTA is taking place from the 28 June – 1 July 2017 in New York.

**14 DATE OF NEXT MEETINGS:**

- Wednesday 15th March 2017 - London
- Wednesday 11th October 2017 - London

**15 FOR INFORMATION ONLY:**

Papers attached for information were:

**- Transplant activity report for August 2016 – BAG(16)23**

**- Minutes of LAG meeting : 11 May 2016 – BAG(16)24**

**- Intestinal Patient Consent – BAG(16)25**

**Administrative Lead – Kamann Huang**